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There's No Place Like Home

Meeting the Housing Needs
of Families of Children with
Special Health Care Needs

**A Report for
Franciscan Children's Hospital
and Rehabilitation Center
Boston, Massachusetts**

Funded by
The Deborah Munroe Noonan Memorial Fund
u/w/o Frank M. Noonan
Fleet Bank of Massachusetts, N.A., Trustee

December 1994



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Meeting the Housing Needs of Families of Children with Special Health Care Needs

Prepared by
Lisa A. Sofis, MPA

For Franciscan Children's Hospital
and Rehabilitation Center
Boston, Massachusetts
December 1994

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DEDICATION

This report is dedicated to the parents of children with special health care needs who took the time from their busy lives to complete our questionnaire. Their comments offer a fitting prologue to this report:

Presently, the family bathroom and my son's bedroom are on the second floor of our house. Unfortunately as he gets older it is more difficult for him to climb the stairs and he is too heavy to carry. He does have a progressive disease and we speculate he will be in a wheelchair permanently within the next 3 or 4 years.

The Housing Authority has a waiting list of 5 years. Meanwhile I pay 80% of my income for rent but at least we are in a safe neighborhood.

My family and I live in Section 8 subsidized housing. It has been a blessing and has kept us from being homeless.

My child was recently placed in a pediatric nursing home. One of the major reasons was the lack of space for a nurse to care for him.

When you have a child in a wheelchair your home is never big enough.

EXECUTIVE SUMMARY

Finding appropriate and affordable housing is a challenge for any family. Families of children with special health care needs have even more challenges to meet. These families care for children with a wide range of medical needs. Their children may rely on mechanical ventilation, they may use wheelchairs, and they may require intravenous feeding. If the housing situations are not appropriate, a prolonged hospital stay may occur. This is devastating for child and family, and costly for society.

As recently as 15 years ago, many of these children would not have survived. The technology required to care for those who did survive was generally available only in a hospital setting. Today, home care for children with complex medical needs is common. This dramatic shift reflects 1) advances in medical technology, 2) shifts in societal attitudes, and 3) availability of funding to pay for home-based care.

With the shift to home-based care, the need for appropriate housing has become critical. What do we mean by appropriate housing? A child with special health care needs may require a ramp to enter and leave the home, storage space for bulky medical equipment, or a backup generator system for life support equipment. Adaptive devices may be required so the child can open doors, get in and out of a bathtub, or carry out other simple tasks. In cases where families rely on home nursing companies to assist with in-home care, housing must be located in a neighborhood to which nursing personnel are willing to go 24 hours a day.

This study on the housing needs of families of children with special health care needs was funded by a grant from the Deborah Noonan Memorial Fund, Fleet Bank of Massachusetts, N.A., Trustee. This grant was administered by The Medical Foundation, Boston, a health promotion agency which also provides grants management and advisory services. The study was carried out over a one year period under the direction of staff of Franciscan Children's Hospital and Rehabilitation Center. It reflects a growing concern on the part of parents and caregivers that housing problems limit their capacity to provide optimal care for children at home. A project Advisory Board, including housing experts, health care providers, agency staff, and parents, lent its support and knowledge to the project.

Over 600 parents of children with special health care needs responded to the study's comprehensive survey of housing needs. The survey reached many families (about 60% of respondents) with children who need assistive technology to survive. More than three-fourths of the families surveyed reported a current unmet need or future need for housing adaptations. Excessive cost was the reason most frequently cited for not making adaptations.

The study also collected information from staff of five Boston hospitals that care for children with special health care needs. Hospital personnel identified seven children who were inpatients at the time of the survey whose discharge had been delayed for periods ranging from 45 days to 21 months. A conservative estimate of the cost of delays in 1993 was \$425,950, 80% of which was incurred by a single child. By the time this child was discharged after a delay of over two years, the estimated cost was \$800,000.

Executive Summary Recommendations

1. Expand statewide availability of resources for home adaptation.

In a survey of parents of children with special health care needs, 68% of those who needed to make home modifications, including middle income as well as low income families, lacked funds to do so. Specific strategies to expand resources for home adaptation are:

- Establish a statewide home modification program using a portion of the Commonwealth's federally allocated Community Development Block Grant or "HOME" funds.
- Reestablish the Department of Public Health's Housing Adaptation Program which operated from 1984 to 1989 and paid for adaptations for 112 families.
- Modify existing Massachusetts Housing Finance Agency's loan programs to make them more responsive to families of children with special health care needs.
- Support community-based programs like "Rampathons" where local construction companies donate labor and materials.
- Create incentives for financial institutions to provide low interest loans for home modifications.

2. Make families of children with special health care needs a priority for state and federal housing programs.

Eleven percent of families surveyed reported being on waiting lists for subsidized housing, or for housing vouchers or certificates, many for long periods of time. Prioritization would move these families to the top of the list.

3. Improve access to timely, accurate information on accessible housing and other housing resources.

This study found that many families were unaware of existing resources. Strategies which would increase access to information include:

- Fully fund the Massachusetts Rehabilitation Commission's Housing Registry and ensure that outreach for the registry targets families of children with special health care needs.
- Distribute existing government publications which offer guidance on housing programs and resources to providers who come in contact with families of children with special health care needs.
- Ensure that families are informed of their rights under the Fair Housing Act.

4. Improve access to information, technical assistance and resources for home modifications.

Almost a third of families surveyed said they lacked information they would need to modify their homes. Proposals to address these gaps are:

- Use public-private partnerships to expand resources available to families of children with special health care needs. Tax credits are one way to support access to low cost building materials for families of children with special health care needs.
- Private industry should offer "how-to" programs for families needing home adaptations.
- State agencies should collaborate with programs like City Year to provide families with information, labor and materials on home modification.

5. Assess current and future housing needs of families of children admitted to hospitals and identify resources to address those needs.

Given the human and financial costs of delayed discharge, assessment of family housing needs should be initiated as soon as possible during an admission. Specific steps include:

- Use or modify the discharge planning instrument created for this project to determine whether individual children are at risk for delayed discharge due to inadequate housing so that unmet needs can be addressed in a timely way.
- Train hospital staff to identify family housing needs and link families to housing resources.

6. Ensure that all families have access to home nursing and other services which make it feasible to care for children with special health care needs in the home.

Although this project focused on housing needs, access to in-home services emerged as a closely related issue. Of the families surveyed, 21% reported an inability to obtain adequate or consistent services in their home. In some cases, this gap resulted in discharge delays.

- The Massachusetts Legislature should establish a working group (including family representatives) to examine delivery of home medical services to children in the state and to identify obstacles to care.

These recommendations reflect the range of options available to meet the challenges of home care for children with substantial special health care needs. They represent an effort to devise social policy as advanced as the medical technology that keeps more and more children alive.

PREFACE

In 1993, the Deborah Munroe Noonan Memorial Fund, Fleet Bank of Massachusetts, N.A., Trustee provided grant funding for a one-year project entitled "*Unmet Housing Needs of Families of Children with Special Health Care Needs*." The grant was awarded to Franciscan Children's Hospital and Rehabilitation Center in Boston. Co-principal investigators for the project were the Government Affairs Liaison at Franciscan Children's Hospital, who was responsible for administrative oversight, and the Director of the Division for Children with Special Health Care Needs of the Massachusetts Department of Public Health, who served as chair of the project Advisory Board. The hospital hired a project coordinator to implement and coordinate day-to-day activities beginning in November 1993. The project continued through November 1994.

The first task of the project coordinator was to establish an advisory group to provide technical expertise and guidance to the project. The Advisory Board included members of an ad hoc committee which had met during the spring of 1993, prior to the project, to discuss housing concerns of families of children with special health care needs. The work of this ad hoc group had provided the base from which the housing needs proposal was written. The Board, like the ad hoc group, included housing advocates, parents, physicians, nurses, hospital social workers, architects, public sector housing policy makers, legislators, and child health advocates. The Board convened four times during the project year.

The project proposal identified three objectives for the project, all of which have been met:

- A needs assessment was completed. Parents and health care providers were surveyed and data were gathered on the extent and nature of housing requirements among Massachusetts families of children with special health care needs.
- A discharge planning questionnaire focusing on family housing needs was developed for use by social workers, case managers, care coordinators, discharge planners and others. This instrument yields a comprehensive picture of a family's current and future housing needs based on their child's medical condition and other circumstances. It is intended to prevent housing crises that many families face at the point of hospital discharge.
- A set of policy recommendations was defined by the Advisory Board based on the project's findings. While the discharge planning instrument addresses needs of individual families, these recommendations address broad policy areas where change is needed if the general housing picture for families is to improve.

Three subcommittees were formed to address the three project objectives. These groups, which focused on the needs assessment, the discharge planning instrument, and housing policy, met regularly throughout the year.

This report reflects the needs assessment and policy efforts of the project. It includes: an overview of the special housing needs of families of children with special health care needs, survey findings indicative of the nature and extent of unmet housing needs, and recommendations for changes in policy to improve the housing circumstances of these

children and their families. In addition, an outline of the discharge planning instrument, which was developed in response to the second project objective, is included as Appendix A. Parents of children with special health care needs take on very significant responsibilities when they choose to care for and raise their children at home. In addition to the universal responsibilities of parenthood, these mothers and fathers coordinate and provide a good share of the medical care of their children. It is our hope that by clarifying the housing issues which confront these families, we can, as a community, respond more effectively to their needs.

INTRODUCTION

Children with Special Health Care Needs

Understanding the housing needs of families of children with special health care needs requires an understanding of who these children are and the range and nature of their special needs. In the United States, an estimated 10-20% of children have a chronic illness or health condition; 7% are believed to have a condition serious enough to cause functional limitation, fair to poor health or both. These statistics reflect the findings of health surveys conducted annually by the federal Department of Health and Human Services. There are no equivalent studies on a statewide basis, however, that would yield specific figures for Massachusetts. Our best estimates of childhood disability in this state come from applying national rates to our childhood population.

Applying the 7% figure to the Massachusetts childhood population yields an estimate of 94,715 children with special health care needs in this state, including children who fit a very broad definition of special health care needs. Within this large group, we can identify a subset of children with the most complex medical needs. These are children who depend on medical technology, such as mechanical ventilation, to stay alive. Because their medical needs are so intense, a specific count of these children has been conducted in this state.¹ Today, more than 1,500 Massachusetts children survive with the use of such equipment. Others included in the 94,715 figure are children with orthopedic or neurological disabilities, children with chronic conditions such as diabetes or asthma (the most common cause of functional limitation in children), or children with mental illness or mental retardation. Clearly, both the nature and the severity of a child's special needs will influence family housing requirements. In this report we focus on families of children with physical disabilities or serious chronic conditions, but it is important to note that all kinds of disabilities may result in special housing needs.

Changes in Care

New technology has not only made it possible for children with complex needs to survive longer, it has also made their care outside the hospital setting feasible. For example, sophisticated mechanical ventilation equipment can now be set up in a home. This means that children who would have been raised in institutional settings can now grow up at home.

A child who relies on mechanical ventilation needs a pump that is approximately the size of a large television console and tanks of oxygen. These oxygen tanks need to be kept separate from any potential fire hazard. In addition, the child might require an intravenous feeding pole and associated supplies, since mechanical ventilation can make nutrition by mouth difficult. While this technology imposes some challenges, the benefits of mechanical ventilation at home are dramatic. A child who relies on this technology may be able to play, interact with family and friends, attend school and lead a full, productive life.

¹ Palfrey, J., Haynic, M., Porter, S., et al. Prevalence of Medical Technology Assistance Among Children in Massachusetts in 1987 and 1990. Public Health Reports. 1994; 109: 226-233.

Along with technological changes, societal attitudes toward disability have shifted dramatically in recent years. There is increasing social acceptance of home care for children who would have been institutionalized in the past. While communities vary in their willingness to support and provide accommodation for families who care for children with disabilities, norms are clearly shifting away from stigmatization and towards acceptance.

Changes in financing, reflecting the shifts in both technology and attitudes described above, make it possible for more families to pay for medical care for a child who receives care at home. Although Medicaid pays for virtually any child who is hospitalized for more than one month, when that same child comes home family income is taken into account in determining eligibility. This means that a family must become impoverished in order to be financially eligible for Medicaid assistance to care for their child at home. Now, states can seek waivers of federal Medicaid eligibility requirements to permit payment for home care of children with complex medical needs without regard to family income. For a "Katie Beckett" waiver, as these are called, to be applicable, a state must be able to demonstrate that home care is less costly than institutionalization for each particular child.

Thus three factors converge at present to promote home care for children with special health care needs: new technology, changed societal attitudes, and the availability of funds to pay for home-based services.

The Need for Housing

With increased feasibility of home-based care for children, the need for appropriate housing becomes critical. The need for a safe, nurturing home is certainly not unique to families of children with special health care needs. Finding appropriate, affordable housing is a challenge for any family. But it is a special challenge for families of children with special health care needs. For low income families, it may be impossible. For these particular families, housing problems may become insurmountable, resulting in hospitalization continued beyond medical necessity because there is no place else for the child to go. This is devastating for affected families and costly for society.

The specific housing needs of a family whose child has special health care needs vary depending on the child's diagnosis, health status, functional status, and age. Housing needs may also vary depending on the health and fitness of the parent -- how able the parent is to carry medical equipment or to lift the child may determine the need for a first floor bedroom, for example. Some other specific needs which may arise are: adequate room for oxygen tanks and other equipment, ample electrical wiring and outlets, emergency backup systems for equipment such as ventilators and heart monitors, wide doorways and low thresholds to permit wheelchair passage, and enough bedrooms so that the child can sleep alone if medically necessary. Adequate space in the home also ensures much needed privacy for all family members in situations where there may be nurses, therapists and others in and out of the home on a regular basis.

Note that special housing needs go beyond the structure of the home itself, however. A family that relies on a home care agency to provide in-home nursing for a child who

needs ongoing care or monitoring must have adequate housing in a neighborhood in which home care nurses feel they will be safe.

While there is no data available on the number of Massachusetts children with each specific type of medical condition, there are, as noted above, national figures from which estimates can be derived. Data related to family housing needs and resources have been completely lacking, by contrast. There is no source of state or national information to indicate how many families are likely to need various kinds of housing supports. Subsequent sections of this report rely, therefore, on original data collection efforts to characterize the scope and nature of unmet housing need.

This report examines the housing needs of families of children with special health care needs from the health care provider perspective, looking at the experiences of local hospitals with delayed pediatric discharge, and from the parent perspective, focussing on the realities of caring for a child in the home. A telephone survey of area providers and a written, mailed questionnaire for parents provided the data which form the basis for this report. (See Appendices A-D for the provider survey questions and the parent questionnaire.) The sections which follow present findings from both of those efforts.

PROVIDER PERSPECTIVE ON FAMILY HOUSING NEEDS

A critical indicator of inadequate housing is delayed hospital discharge. In fact, the prolonged stay of a single child for over one year in a hospital, along with more general reports of housing as a major concern of families, were the catalysts for this project. This child's case, which is profiled below, reflects both the range and the impact of housing problems which may confront the family of a child with special health care needs.

Delayed Hospital Discharge: One Child's Story

J. is a toddler who is ventilator-dependent, has both tracheostomy and gastrostomy tubes, and uses a modified stroller. His mother, who speaks little English, began her search for a home in the spring of 1992, shortly after her son's hospital admission. She located a subsidized apartment in an urban community, near the extended family on whom she relied for assistance in her child's care, and moved in while J. was still hospitalized. She was forced to move before her child was discharged, however, because the hospital could not find home care nurses willing to travel to her neighborhood. Other apartments which the mother located presented similar problems. Some were in neighborhoods viewed as unsafe by home nursing agencies, some had inadequate bedroom capacity. The latter was not simply a matter of comfort or preference; J. needed a separate bedroom to accommodate overnight nurses and all of his equipment. The mother also encountered difficulties meeting potential landlords' requirements for security deposit and first month's rent. After a two year search involving hospital personnel and other social service agencies, the mother finally located an apartment that met most of her family's needs and the child was discharged. At that point the child had spent virtually his entire life in the hospital. He had been hospitalized beyond medical necessity for over two years at a cost of over \$800,000 by the time the housing issue was resolved.

As this report is being written, J.'s mother is negotiating with the company that manages her apartment to provide access through the basement so she can get her child in and out without going up stairs. In the meantime, she must maneuver J.'s wheelchair and heavy equipment up and down several steps.

Survey of Five Boston Hospitals

In January 1994, five Boston hospitals were contacted to determine whether they had experienced delayed pediatric discharges due to housing problems. Three were acute care facilities: Massachusetts General Hospital, New England Medical Center and Children's Hospital Medical Center. These hospitals are geared to short-term stays during which intensive medical intervention occurs. The remaining two, Franciscan Children's Hospital and Rehabilitation Center and Spaulding Rehabilitation Hospital, are rehabilitation facilities where longer term stays may occur. Franciscan Children's Hospital is a specialized pediatric facility while Spaulding serves patients of all ages.

Given financial pressure from insurers to discharge patients promptly or lose reimbursement, delayed discharge creates a serious problem for hospitals. Hospitals are not anxious to retain children as inpatients unless there is a major obstacle to discharge. If the obstacle involves housing, it may reflect either that the family has no home to which the child can be brought or that the home is seriously inadequate for the child. In some instances, discharge to a shelter becomes the immediate, short-term solution.

In the five hospital survey, personnel in charge of pediatric discharge planning were asked to describe instances, current or during the prior year, of delayed pediatric discharge related to housing problems. None of the five hospitals surveyed routinely collects information that would permit a precise response to this query, so staff had to rely on personal recollection and discussion with colleagues. As a result, reporting of historical experience may have understated the true extent of the problem. A complicating factor for hospital personnel trying to respond to this survey is that prolonged hospital stays would have been justified for many children, given their substantial medical needs, if parents had not been willing and able to take on the challenge of home care.

Ongoing Delayed Discharge

The two rehabilitation hospitals reported six instances of prolonged hospitalization due to housing problems which were ongoing at the time of the study (winter 1994). All five hospitals reported delays in discharge during 1993. They also noted that acute hospitals have the option of transferring some patients who require after-hospital care to other locations, such as Franciscan Children's Hospital or Spaulding, which provide long term rehabilitation. When this occurs housing inadequacies may not be addressed until the time of discharge from the second facility.

Table 1 presents results from the five hospitals. Staff were asked to determine the length of delayed discharge for each current case of which they were aware. Reported delays ranged from 45 days to 21 months. Although the specific reasons for delay varied in each situation, common factors cited by hospitals were:

- Poverty
- Lack of handicapped accessible, affordable housing
- Competing needs, such as the need to be near supportive family members, which limited housing options
- Language barriers for families confronting complex bureaucracy in the public housing system
- Housing discrimination based on age, race, income or the child's condition

TABLE 1
Ongoing Hospital Discharge Delays at Time of 1994 Survey

HOSPITAL ^a	ONGOING DELAYS	BED COST PER DAY *	# OF EXCESS DAYS	ESTIMATED COST OF DELAYS
Rehab A	4 ^b	\$965	1095	\$1,056,675
Rehab B	2	395	150	59,250
Hosp A	0	806	-	-
Hosp B	1	800	na ^c	-
Hosp C	0	710	-	-

^a The five hospitals surveyed are referred to by letter here and on subsequent figures to avoid inappropriate comparisons among hospitals.

^b Not including 2-4 delays which involved both housing and parental fitness issues

^c Data not available

* Semi-private, pediatric rate (source: hospitals' annual reports filed with Massachusetts Rate Setting Commission)

Estimated Costs

Table 1 also provides estimates of the costs of ongoing delays up to the day on which the survey was conducted. Because inpatient care is expensive, even a single day of delay can cost up to \$1,000. Figures cited may underestimate total cost; they only reflect semi-private, pediatric bed cost and do not include ancillary charges, such as pharmaceuticals or specialized medical care. Even with this conservative bias, delayed discharge results in a substantial financial cost.

Examples of Delayed Discharge

Case histories provided by hospital staff revealed a variety of family circumstances and housing concerns.

- Difficulty correcting a cockroach infestation resulted in a delay of more than a month in one child's release. Nurses were so concerned about nighttime safety and cleanliness that the hospital provided \$200 to move the family to a safer location.
- Inadequate electrical supply in a family's trailer prolonged another child's hospital stay. He was on dialysis and his equipment required a steady power source.
- A child just days away from discharge could not go home because the oxygen equipment company truck could not get up his family's driveway. The road was built on landfill and could not support the weight of the truck.

Delayed Discharge During 1993

Staff of all five hospitals reported cases of delayed discharge during 1993. Numbers were quite varied across sites, ranging from 1 to 15 pediatric patients who had remained hospitalized beyond medical necessity. (see Table 2).

TABLE 2
Delayed Discharges and Associated Costs, 1993

HOSPITAL	# OF DELAYS	BED COST PER DAY
Rehab A	2*	\$919
Rehab B	8	395
Hosp A	15	731
Hosp B	1	800
Hosp C	2	670

* Costs incurred by a third case are described below.

As noted above, hospital personnel cannot pinpoint the dates on which particular children could have been discharged had appropriate homes been available. As a result, we don't have precise information on the cost associated with historical delays. In order to provide any sense of the total cost of delayed discharge we must rely on estimation. Data we do have make clear that the duration of delay varies widely from child to child. If, for purposes of estimation, we assume an average delay of five days per child and apply this estimate to the number of delays recalled by staff at each hospital, we derive a minimum cost estimate of \$90,515 plus the \$335,435 actually spent during 1993 on J., the child described in the case study. Thus a conservative estimate of the cost of delayed pediatric discharge in 1993 in these five hospitals, based on bed cost alone, was \$425,950.

Beyond financial ramifications, unnecessary, prolonged pediatric hospitalizations can affect a child's development and the well-being of child and family. Staff reported that hospitalized children were often bored and, when hospitalized over a long period, slower in reaching developmental milestones. This was due to the restricted atmosphere of the hospital and the limited time staff had available to play and interact with patients. For families, delays entailed prolonged periods of travel back and forth to the hospital and extended disruption of family life.

Although the information from hospitals is anecdotal, it suggests the extent and ramifications of delayed discharge. Findings from the parent questionnaire highlight different, yet equally challenging housing issues facing families of children with special health care needs.

PARENT PERSPECTIVE ON FAMILY HOUSING NEEDS

Survey Sample

Project staff developed, pre-tested and distributed a written questionnaire to parents across the state to assess the housing needs of families of children with special health care needs. The project collected 631 completed surveys between May and September of 1994.

The programs from which parents were identified for participation in the survey were:

1. The Case Management Program of the Department of Public Health, Bureau of Family and Community Health, which provides care coordination for Massachusetts children who have serious chronic illnesses or complex medical needs (see Case Management Eligibility Criteria, Appendix E).
2. Early Intervention (EI) Programs, which are located across the state, provide developmental services for children birth to three years of age who manifest or are at substantial risk for developmental delay. EI serves children at risk for many reasons, not only health. Therefore, the survey was offered to parents of children who had a condition that might require housing adaptations.
3. The Massachusetts Hospital School, a state-funded school in Canton for children ages 8 to 22 with significant disabilities.
4. Pediatric inpatient units of Franciscan Children's Hospital and Rehabilitation Center in Boston.
5. The Federation for Children with Special Needs, a family-run support and advocacy organization.
6. New England Medical Center, a tertiary care hospital located in Boston.

The survey and accompanying materials were available in English and Spanish. (See Appendix F for details on survey administration and response).

Survey Overview

Parents were asked to respond to questions on their child's disability, the family's current housing situation, and their need for a variety of home adaptations. Adaptations were defined to include structural changes such as ramps, bathroom expansions, widened doorways, and increased floor space, improvements to electrical and air circulation systems, and smaller scale changes like grab bar installation or doorknob and faucet alterations. Survey questions also addressed home-based services, home ownership status, and family demographics. Collection of data on these non-housing variables (Table 3, pages 16 and 17) was intended to permit a deeper understanding of the many factors that might have an impact on housing needs.

TABLE 3
Demographic Profile of Children with Special Health Care Needs
and their Families

CATEGORY (# OF RESPONSES)	#	%
CHILD'S SEX (n=631)		
Male	359	56.9
Female	272	43.1
CHILD'S AGE (n=631)		
0-18 mo.	55	8.7
19 mo.-2 yrs.	130	20.6
3-5 yrs.	163	25.8
6-12 yrs.	172	27.3
13-17 yrs.	60	9.5
18+ yrs.	50	7.9
Unknown	1	0.2
CHILD'S RACE/ETHNICITY (n=626)		
White, non-Hispanic	488	77.9
Hispanic	76	12.1
Black, non-Hispanic	34	5.4
Asian/Pacific Islander	12	1.9
Amer.Indian/Alaskan Native	1	0.2
Other	15	2.4
CHILD'S INSURANCE^a (n=625)		
MassHealth (Medicaid)	453	72.4
Private	361	57.7
CommonHealth	88	14.0
CHAMPUS	10	1.6
Medicare	9	1.4
No Insurance	3	0.4
Other	4	0.6
PRIMARY LANGUAGE IN HOUSEHOLD (n=631)		
English	532	86.5
Spanish	63	10.2
Portuguese	6	1.0
Haitian Creole	6	1.0
French	3	0.5
Vietnamese	3	0.5
Cambodian	2	0.3
Other/Unknown	16	2.5

^a Responses exceed 625 as many children had more than one type of health insurance.

TABLE 3 (cont.)
Demographic Profile of Children with Special Health Care Needs
and their Families

CATEGORY (# OF RESPONSES)	#	%
LIVING SITUATION (n=627)		
Own Home	341	54.4
Rent in private housing	198	31.6
Rent in public housing	57	9.1
Relative's home	22	3.5
Friend's home	1	0.2
Shelter	1	0.2
Other	7	1.1
FAMILY'S INCOME (n=609)		
\$0-9999	98	16.1
\$10,000-29,999	211	34.6
\$30,000-49,999	180	29.6
\$50,000+	120	19.7
CITY OF RESIDENCE (5 highest) (n=618)		
Boston	52	8.4
Worcester	27	4.4
Springfield	17	2.8
Holyoke	16	2.6
Lowell	12	1.9

Summary of Findings

Unmet housing need is widespread among families of children with special health care needs. Two distinct types of need emerged. The greatest need was for adaptations to a current home; 77% of respondents indicated a definite or possible future need for adaptations. Of those who expressed a definite need, 87% stated that they were unable to make needed changes on their own due to lack of resources, lack of information or other constraints. Some families, however, described needs which could not be met within their current home. These included 15% of respondents who needed to make adaptations but could not because their landlord prohibited them and 5% of respondents living temporarily with relatives, friends or in shelters. Some families did report that they had been able to make necessary home adaptations (28%). These families found ways to pay for adaptations out-of-pocket, or were among a few who obtained financial assistance or other resources from their communities.

Child's Health Status

In order to assess the relationship of health condition to housing need, the questionnaire asked parents to classify their child's main disability (as defined by the parent) by identifying the affected body system. Most frequently reported were neurological, or nervous system, disorders (see Table 4). These disorders, affecting 51% of the 630 children in this sample, may constrain a child's ability to walk or move about independently. The next most commonly reported category was congenital anomalies (conditions present at birth) which affected 10%, followed by respiratory disorders (8%), digestive disorders (7%) and musculoskeletal disorders at 6%.

TABLE 4
Main Disability Categories

MAIN DISABILITY ^a (n=631)	# OF RESPONSES	% OF TOTAL
Neurological	324	51.3
Congenital Anomalies	65	10.3
Respiratory	48	7.6
Digestive	43	6.8
Musculoskeletal	36	5.7
Mental/Emotional	23	3.6
Cardiovascular	18	2.9
Endocrine	16	2.5
Genitourinary	10	1.6
Special Sense Organs	10	1.6
Learning & Cognition	8	1.3
Growth Impairment	7	1.1
Neoplastic Disease	6	1.0
Hemo/Lymphatic	6	1.0
Immune System	5	0.8
Multiple Body Systems	3	0.5
Infectious Disease	2	0.3
Unknown	1	0.1

^a As defined by parents

To characterize health status more precisely, parents were also asked to identify their child's primary diagnosis. Of 628 children whose parents responded to this question, the most frequently reported primary diagnosis was cerebral palsy, affecting 22%, followed by spina bifida affecting 7%. Other frequent diagnoses were bronchopulmonary dysplasia (a respiratory disorder), intestinal pseudo-obstruction (a digestive disorder); seizure disorders, and muscular dystrophy (see Table 5). Overall, parents identified more than 100 different diagnoses.

TABLE 5
Most Common Primary Diagnoses

PRIMARY DIAGNOSIS (n=627)	# OF RESPONSES	%
Cerebral Palsy	136	21.7
Spina Bifida	42	6.7
Bronchopulmonary Dysplasia	27	4.3
Seizure Disorder	23	3.7
Intestinal Pseudo-Obstruction	23	3.7
Muscular Dystrophy	21	3.3

Many families noted that their child's health status affected mobility. Excluding families of children under 18 months of age, (since children this young might not have begun walking) more than 18% said that their children were carried around the home. Another 21% reported use of a wheelchair as the child's primary way of moving about.

In 606 responses to a question on use of medical technology, parents reported that 60% of children were dependent on one or more forms of technology for survival. The most common device was a feeding tube; 56% of the 362 technology-dependent children used this apparatus (see Table 6). Adaptive devices such as bathtub seats or a Hoyer lift (for moving a child in and out of bed) were used by more than 58% of children in 605 families.

TABLE 6
Selected Equipment Used by Children Dependent on Technology^a

MEDICAL DEVICES/EQUIPMENT (n=362)	# OF RESPONSES	%
Feeding Tube	202	55.8
Suctioning Equipment	133	36.7
Oxygen	131	36.1
Apnea Monitor	74	20.4
Tracheostomy Tube	70	19.3
Ventilator	42	11.6
Genitourinary Device	27	7.4
Central Venous Line	24	6.6
Colostomy/Ileostomy Pouch	12	3.3
Dialysis Equipment	1	2.7
(Other)	157	43.3

^a See Appendix G for descriptions of equipment

Because of their complex medical needs, many children in the sample group required some type of service within the home; out of 620 households responding to this question, 70% said their child obtained health, educational, therapeutic or other services in the home.

Age and Sex

The average age of the children in this sample was 6 years. This young average age can be attributed to the fact that families tend to need DPH Case Management, which was the major source of respondents, when their children are young and they need help to set up arrangements for care. All children in Early Intervention are age 3 or younger, so this group also lowered the average age of the overall sample. Boys outnumbered girls among the sample children, 57% to 43% of the 631 total.

UNMET HOUSING NEEDS

The survey listed 25 possible home adaptations. Parents were asked to fill in each box with the number which best described their need for each adaptation:

- 1) I/We currently need this
- 2) I/We might need this
- 3) I/We put this in
- 4) This was already there
- 5) I/We do not need this

A family could fill in "I/we might need it" either because they expected their child's growth and development (i.e. from infant to toddler) to alter their requirements, or because predictable change in the child's condition could be expected to influence housing needs.

Of the 631 families who responded to the questionnaire, 485, or 77%, stated that they had a definite or possible need for one or more home adaptations. Thus a substantial majority of families had some type of unmet housing need or expected to have a need in the future. This level of need reflects the national trend towards home care for children with increasingly complex medical conditions and can be expected to increase as the trend continues.

Table 7 shows the adaptations which parents stated they "needed or might need" most frequently. The variety within this list indicates the range of needs that may be associated with caring for a child with special health care needs at home. A single child may require a ramp to enter the home, bathroom modifications and special provisions for electricity in case of power failure.

TABLE 7
Most Commonly Needed Adaptations^a

ADAPTATION	%	ESTIMATED COST ^b
Bathroom Expansion (n=577)	40	\$4000
Air Circulation/Ventilation (n=567)	36	\$7500
More Space for Medical Equipment (n=576)	35	\$500-1250
Backup Electrical Generator (n=568)	35	\$5000
Ramp (n=588)	33	\$3000

^a Regardless of disability

^b Cost estimates provided by Adaptive Environment Center, Boston

Space within the home is often at a premium. As noted earlier, many children in the survey group depend on technology to meet their medical needs. Some types of medical equipment such as ventilators, oxygen tanks, and feeding apparatus, require substantial floor space. Other items, like diapers and special nutritional formulas which are purchased in bulk from supply companies, may end up in hallways or stairways for lack of a storage area.

Another factor related to the need for extra space in the home was the strong concern expressed by parents about privacy for family members. When parents were asked, "If you could only make one adaptation to your home, what would it be?" the most common response, offered by 20% of parents, was "More privacy for my child or my family." Parents also mentioned the stress felt by the whole family when a child had to sleep on the first floor in the only common room in the home because interior stairs were a barrier to second floor bedrooms. Families of children who received therapies or nursing care in the home were particularly likely to complain about the lack of privacy and overcrowding.

Many housing needs cited by parents involved either the safety or the growth and development of their child with special health care needs. For a child who uses a ventilator or other electrical equipment, poor wiring or inadequate backup electrical generation could be life-threatening. Getting in and out of the front door in a wheelchair raises critical psycho-social issues. The inability to enter and leave the home can greatly limit a child's opportunity to interact with others, to go to school or to social activities, thus impeding emotional and cognitive development. For children with special health care needs, home adaptations substantially improve their quality of life. In fact, for some children, home adaptations may determine whether or not they can be cared for in the home.

Unmet Needs and Age of Child

The age of the child with disabilities can affect how families perceive the need for adaptations. Only 38% of parents with a child under 18 months felt they had a "definite" housing need, as compared to 77% of parents with a child between the ages of 6 and 13. This may be attributable to the fact that outcomes of some diagnoses are uncertain when a child is diagnosed at a young age. Parents often need to wait and see how a child progresses over time before they can fully assess the scope and severity of their child's disability or illness.

Families with younger children more often reported "a possible need" than those with older children. Of families with a child under 3, 21% thought they might have some type of need in the future, as opposed to 9% of families with a child in the 6-13 year old range.

Unmet Needs and Family Demographics

The size and configuration of our survey sample does not permit detailed analysis of links between housing needs and family demographic factors such as race, language and income. Race and language limit options where housing discrimination exists. Income restricts choices because of housing costs, particularly for appropriately adapted homes.

Unmet Needs and Public Housing

One striking set of findings from the survey have to do with unmet housing needs of families living in public housing. Of the 57 families living in public housing, 68% had one or more unmet housing needs including 32% who reported need for a ramp and 25% who reported need for an expanded bathroom. These types of adaptations would be available to families if they lived in handicapped accessible publicly subsidized units. The extent of expressed unmet need highlights lack of access to such units in public housing. Housing authority staff from different communities who provided input to this project stated that there are accessible units within their systems, but that difficulty in locating appropriate tenants leads them to fill the units with individuals who do not require their special adaptations. Many parents, on the other hand, reported long waiting lists for handicapped accessible apartments in neighborhoods to which home nursing agencies are willing to travel. They also noted a dearth of 3 and 4 bedroom units, which may be necessary to accommodate a family.

Families' difficulty in obtaining subsidized housing is further reflected by the 11%² of families on one or more waiting lists for some type of housing assistance. These inadequacies within the subsidized housing system place particular stresses on low income families who, as a rule, have few housing options.

UNMET NEEDS AND HOME CARE SERVICES

Appropriately adapted housing is a necessary condition for home care of a child with special health care needs, but it is not, for many children, sufficient. Also critical is access to home-based services. As noted earlier, 70% of families reported that they obtained some type of service in the home, including physical therapy, schooling, and/or bedside nursing care. However, 21% of the 608 families who responded to this question reported that they have had difficulty obtaining home services. As mentioned, a child who cannot get the necessary nursing care at home is at risk for a delayed discharge. Some children have even been rehospitalized when nursing care could not be found, according to staff of one hospital in the five hospital sample.

Of those families that had difficulty getting services, the most often cited reason was "cancellations and/or staff turnover" (42%). This means that even families with insurance coverage available to pay for services were sometimes unable to locate appropriate caregivers. Information from focus groups conducted with home care agencies and from hospital social service staff suggested a further issue underlying staffing problems. These health care providers indicated that neighborhood location and perceived safety made it difficult for home nursing agencies to recruit nurses for some families, particularly for evening or overnight shifts. It is possible that what has been presented to parents as high rates of turnover and cancellations is actually an unwillingness by agency staff to provide service in particular neighborhoods.

² Percentage based on responses from 600 families.

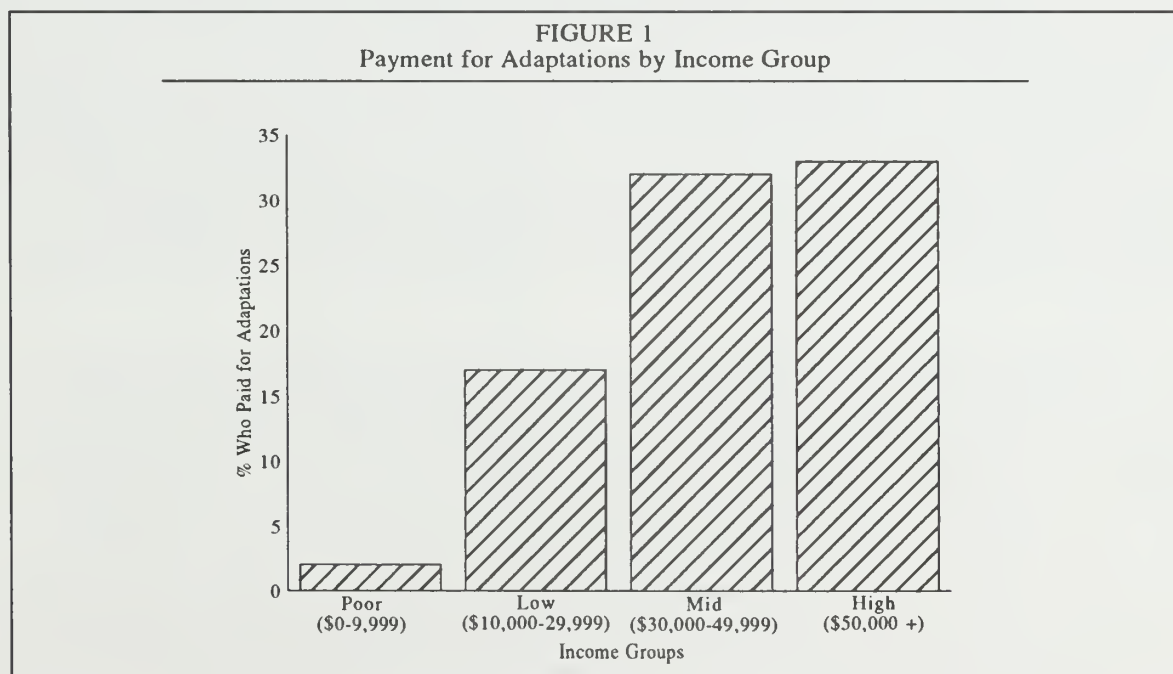
Constraints on access to home-based services place additional stress on families. Parents who are already stretched carrying on family life while caring for a child with complex medical needs may also have to take on full-time nursing responsibility. Or the need for care may oblige the family to seek housing in areas that are beyond their means, or that do not meet other family requirements. Ultimately, if these trade-offs become unmanageable, they may result in permanent out-of-home placement for the child in an institutional setting or in foster care.

The Cost of Adaptations

Lack of financial and other resources are major obstacles to caring for children with special health care needs at home and few existing programs provide resources to help families make adaptations. Of the families who stated they had a current need for at least one adaptation, 68% said that excessive cost was one of the reasons why they had not made these changes. Cost was the most frequent explanation families offered for unmet need for adaptations. Within the sample group, income had no major bearing on whether families felt that cost was an issue; families across all income brackets found it problematic. Of the 609 families who provided income information, 51% reported earnings below \$30,000 whereas only 6% had a family income over \$75,000.

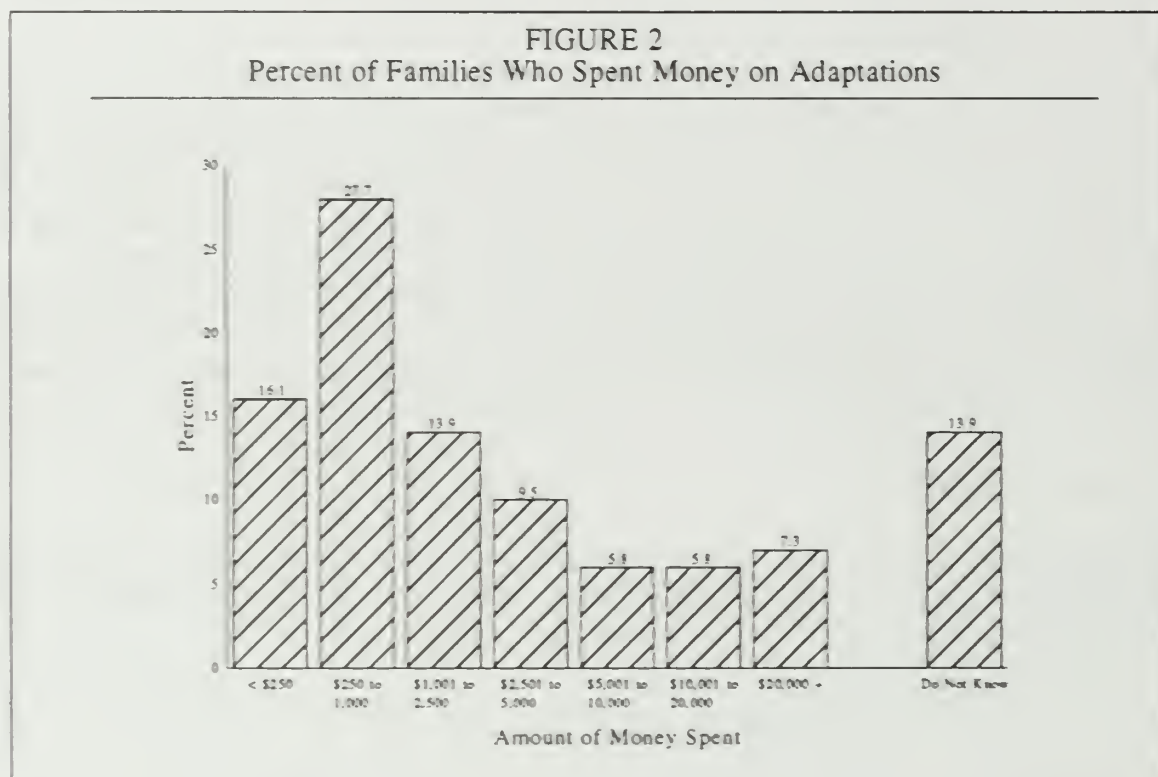
Who Pays for Adaptations

While income was not associated with unmet need, higher income was associated with having made adaptations (see Figure 1). Of the 171³ families reporting that they had already made adaptations, 71% paid for all the work themselves.



³ Families included here are those who responded to all 3 survey questions about having made adaptations. These questions addressed 1) type of adaptation put in, 2) payment source, and 3) cost.

The cost range most frequently reported for completed adaptations was between \$250 and \$1,000. Figure 2 highlights family expenditures for adaptations. At the most expensive end of the range, eleven families incurred costs of over \$20,000. The modifications in these 11 homes included 8 first floor room conversions to bedrooms (at variable cost), 7 ramps (about \$3,000 each)⁴, 7 expanded bathrooms (\$4,000), 7 roll-in showers (\$2,500), 6 electrical rewirings (\$500) and 6 room enlargements (\$9,500). These are among the most expensive adaptations families may need.



The second most frequently reported resource for adaptations was community donations; 19% of families who had made adaptations reported receiving assistance from community organizations such as the Knights of Columbus, which often provide labor and/or materials for ramps.

Only 10 households out of 171 who had made adaptations used insurance coverage as a payment source. Eight of these families were among a group who reported having private insurance with Medicaid coverage as a "wrap-around" for their child. This coverage is available only to children with the most complex medical needs via the waiver described on page 8 or the state-funded CommonHealth program, which permits parents to purchase Medicaid for a child who has been excluded from or has exhausted private coverage as a result of high medical expenses. In these cases Medicaid may have paid for an adaptation as a component of care at home for the child. In general, it is clear that health insurance is currently a very limited resource for home adaptations, even when those adaptations are closely linked to effective care.

⁴ This and other cost figures for adaptations reflect approximate costs for a single item.

Home Ownership

Whether a family owned their own home or rented had a major impact on whether they made home adaptations. Those who owned their own homes were three times as likely to make adaptations as renters. Even when renters and homeowners were in the same income bracket, this difference persisted. This could be attributed to a greater willingness by owners to invest in modifications to the home, as well as to the freedom they have to make changes on their own property.

Existing Resources

Resources and information to assist families with adaptations are limited and families are often unaware of those that exist. Of the 341 families who explained why they were unable to make needed adaptations, 29% indicated that they lacked design skills or did not know how to find building materials. And 26% indicated they did not know how to locate an architect specializing in home modifications or any other source of technical assistance to help them address these needs.

Funding sources, such as federal Community Development Block Grants (CDBG), are also inaccessible and unfamiliar to many families. These grants are given to 30 cities in Massachusetts (based on population) and can be used in part for home modifications by low and moderate income households. However, of the families in need of adaptations, 67% did not live in one of the designated cities and thus did not even have the opportunity to apply for funds.

Under the federal Rehabilitation Act of 1973, as amended, some adolescents may be eligible for vocational rehabilitation services including funding for home adaptations. In addition, individuals who have severe disabilities and need adaptive or assistive devices such as home modifications may receive these under Title VII of the Rehabilitation Act. In both cases, information on these programs is not widely disseminated to families and the programs are underfunded to meet current need.

COMMENTS ON SURVEY FINDINGS

A picture of widespread need emerges from the survey of parents and from exploration of housing issues with hospital staff and home care providers. Barriers to obtaining adaptations pose critical problems for many families; other families do not have homes which may feasibly be adapted to meet their needs. Both kinds of unmet need can result in prolonged hospitalization. More frequently they result in families staying in homes that are unsafe or unnecessarily restrictive for their children with special health care needs or are overcrowded and lacking in privacy for other family members. Many families make trade-offs among needs such as safety of the child, appropriate design to maximize the child's mobility and use of home facilities, family privacy, affordability, and access to home services -- sacrificing one or more to assure that other needs are met. Both the challenge of meeting housing needs and the increased work load that result from lack of housing resources intensify the responsibilities inherent in caring for a child with complex medical needs at home.

Existing resources, such as adapted public housing units and CDBG funding in communities served by that program, are not readily available to families. Conflicting reports from parents and public housing officials about availability of subsidized units may indicate that the public housing shortage is, at least in part, a matter of the distribution rather than the existence of resources. Improving the systems that link families to available resources is the most cost-effective approach to meeting family needs.

CONCLUSION

While it is beyond the scope of this study to completely characterize the effects of unmet housing need, members of the project's advisory group noted the conflict between the social goals of home care for children and the unmet housing need described in the study:

"I am struck by the irony of hundreds of thousands spent on unnecessary hospitalization while even a few hundred dollars might pay a family's security deposit and a few thousand would pay for all but the most expensive adaptations. The \$800,000 spent on one child in one hospital would pay for 270 ramps, 200 bathroom modifications or provide enough funds to construct eight handicapped accessible Public Housing units. This is not good public policy!"

"Parents of hospitalized children struggle to come to the hospital frequently, often travelling considerable distances and sometimes under difficult circumstances, to maintain some semblance of a family relationship with their child. When the child is, at last, medically stable enough to go home, he or she may languish in the hospital simply because parents have been unable to obtain handicapped-accessible housing. This is a social tragedy and an enormous waste of resources."

If, as a society, we are saying "there's no place like home" for children with special health care needs, then we must support policies and programs to make that home a safe and nurturing environment. The recommendations that follow suggest the range of policies and programs available to us.

RECOMMENDATIONS

1. Expand statewide availability of resources for home adaptation.

This study found that 68% of families who needed to make home modifications did not have the funds to do so. Lack of resources affected middle income, as well as low income families, suggesting the need for a variety of types of funding sources. Strategies should include grants for very low income households and low-interest loans for more moderate income households. While some communities do provide low-interest loan and grant programs, 67% of families surveyed did not live in any of 30 communities that have federal home modification (Community Development Block Grant [CDBG]) funds available.

- The Executive Office of Communities and Development (EOCD) should establish a statewide home modification program using a portion of the Commonwealth's allocation of HOME or CDBG funds. This strategy could be implemented cost effectively through existing local programs, such as the home adaptation programs operated by the state's ten regional Independent Living Centers, or through local Community Development Departments. All cities and towns must be served by these initiatives, not just those that receive CDBG funding.
- The Department of Public Health (DPH) Adaptive Housing Program should be reestablished. This program, in operation from 1984 to 1989, financed major modifications for 112 families at a total cost of \$475,000 (an average of \$4,200 per family).
- The Massachusetts Housing Finance Agency (MHFA) should modify its loan programs to ensure they meet the needs of families of children with special health care needs. These changes should: 1) ensure that all MHFA rehabilitation programs include home modification as an eligible activity; 2) provide residents of any city or town access to MHFA loan programs; 3) reestablish very low interest loan programs for households which have a member with a disability.
- Home modification funds should be set aside to support community-based programs like "Rampathons," where local construction companies donate labor and materials.
- Banking regulators should encourage financial institutions to provide low interest loans for home modifications. Such action should partially fulfill federal and state Community Reinvestment Act requirements for these institutions.

2. Include families of children with special health care needs as a priority group for housing programs of the Executive Office of Communities and Development (EOCD), Massachusetts Housing Finance Agency (MHFA), and federal Housing and Urban Development (HUD).

In this study 11% of families said they were on one or more waiting lists for subsidized housing or for federal Section 8 or the Massachusetts Rental Voucher Program (MRVP) certificates or vouchers. Often the duration of the wait lasted months or years. Of those families in public housing, at least 32% had a need for a handicapped accessible unit.

3. Ensure families, advocates, state agency personnel and service providers increased access to current information on existing accessible housing and other relevant resources.

This study found that many families were not aware of existing resources. Maximizing use of existing resources is the most cost effective strategy for improving housing circumstances. It should be seen as a key strategy in conjunction with development of the kinds of new resources suggested above.

- The Massachusetts Rehabilitation Commission's Housing Registry should receive increased funding to make it fully operational. The Registry is a computer database that matches people with disabilities with accessible housing units.
- The Housing Registry should ensure effective outreach to families with children with special health care needs and to agencies serving this population. The Housing Registry Advisory Committee should be expanded to include agencies representing the needs of this population.
- The EOCD publication, "How to Obtain Affordable Housing" and the housing listing maintained by the MHFA should be systematically distributed to all families receiving DPH Case Management services and to case managers, parent and family advocacy groups, housing information and advocacy organizations, hospital social workers and hospital discharge planners.
- Providers and advocates should ensure that families have access to information on their rights under the Fair Housing Act to protect them from discrimination based on their child's condition.

4. Increase families' access to information and technical assistance on home modifications. Enhance the availability of subsidized raw building materials and expand programs which recycle adaptive equipment.

Of the families surveyed, 29% indicated they did not know about design or how to find building materials and 26% said they did not know how to locate someone, such as an architect, who could provide technical assistance.

- State agencies should seek out private companies and non-profit corporations with an interest in home remodeling to develop partnerships aimed at expanding resources available to families of children with special health care needs.
- The state should offer tax credits as an incentive to private companies to offer home building materials to home modification programs at no charge or low cost. Private companies should also be encouraged to offer "how to" workshops free or at low cost to families making home adaptations themselves.
- State agencies should work collaboratively with City Year, Habitat for Humanity, Youth Build, the Massachusetts Assistive Technology program and other groups to provide families with information, labor and materials on home modification.
- Partnerships should be strengthened between equipment recycling programs within organizations such as Easter Seals and parent/family advocacy groups to help meet special equipment needs and keep costs down.

5. Assess current and future housing needs of families of children admitted to hospitals and identify resources to address those needs.

The cost of delayed hospital discharge due to housing problems in five Boston hospitals in 1993 can be conservatively estimated at \$425,950. To avert such unnecessary costs, a housing assessment should be initiated soon after the hospital admission of a child who will have ongoing special health care needs. Currently, questions about housing need may be raised near the time of discharge if they are raised at all. Specific steps to assure early assessment of need include:

- Hospital staff should use or modify the discharge planning instrument created for this project to determine whether children are at risk for delayed discharge due to their family's housing circumstances. Staff should identify family needs early in the hospitalization in an effort to bring about a timely solution.
- The discharge planning instrument should be used as a framework for training hospital social service, discharge planning and case management staff on issues related to housing.

6. Ensure that all families have access to home care, nursing and other necessary home support services.

Although this project focused on the availability of an appropriate physical setting for children with special health care needs and their families, access to home services emerged as a closely related issue. In this study, 21% of families of children with special health care needs were unable to obtain adequate or consistent services in their home. In some cases, this gap resulted in discharge delays. The study identified a range of reasons for lack of services. Strategies to begin to address home care needs include:

- The Joint Committee on Human Services and Elderly Affairs within the Massachusetts Legislature should establish a working group including state agencies, families and key service providers to examine delivery of home medical services to children in the state and to identify obstacles to care.
- Policy options which should be considered by the working group for improving delivery of home care services are:
 - a) Reestablish an Individual Kid Advocacy function (modeled on the program previously within the Office for Children) to ensure access to appropriate home medical services.
 - b) Develop expanded guidelines for insurance coverage of personal care attendants.

APPENDICES

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APPENDIX A
Discharge Planning Instrument
Outline of Contents

- I. General information
 - A. Identifying information
 - B. Diagnosis
- II. Preliminary screen for housing needs
- III. Child's technology needs
- IV. Child's mobility needs
- V. Child's skilled nursing and other home care needs
- VI. Physical structure, location of current home
- VII. Potential need for out-of-home placement

The complete discharge planning instrument is available from:
Deborah Allen, Massachusetts Department of Public Health
150 Tremont Street (7th Floor), Boston, Massachusetts 02111

APPENDIX B

Telephone Survey of Health Care Providers

Respondents were asked to provide:

1. Number of ongoing discharge delays
2. Circumstances surrounding each instance of delay in regard to:
 - Child's medical condition
 - Duration of delay
 - Reason(s) for delay
 - Family housing situation
3. Number of children delayed in 1993
4. Daily charge per bed

APPENDIX C

Questions for Home Nursing Agency Focus Groups

Respondents were asked about:

1. Difficulties confronting families caring for children with special health care needs in the home as observed by agency personnel
2. Perspective of agency personnel on the most significant challenge faced by families in relation to home care for children with special health care needs
3. Frequency with which personnel see the need for various adaptations
4. Extent to which perceived safety issues influence availability of service delivery

APPENDIX D

**On the following pages is of the Housing Adaptations survey for you to reproduce.
(Spanish version is available upon request from Deborah Allen)**

PLEASE PRINT. PLEASE ENTER NUMBERS IN UNSHADED BOXES ONLY.

ID NUMBER:

--	--	--	--	--	--	--	--	--	--

DPH use only

PART A: YOUR CHILD'S HEALTH

Please answer the questions as best as you can. Enter numbers in unshaded boxes only, one number per box. This section asks about your child's health.

1. TODAY'S DATE

month		day		year	

2. CHILD'S DATE OF BIRTH

month		day		year	

3. YOUR CHILD'S GENDER?

1= Male

2= Female

☐

4. WHAT IS YOUR CHILD'S MAIN DISABILITY?

(please choose only one even though there may be more)

01 = Neurological Disorder

02 = Muscle/Skeletal Disorder

03 = Special Sense Organs

04 = Respiratory Disorder

05 = Mental/Emotional Disorder

06 = Digestive Disorder

07 = Immune System Disorder

08 = Genito/Urinary Disorder

09 = Hemo/Lymphatic Disorder

10 = Endocrine Disorder

11 = Cardiovascular Disorder

12 = Neoplastic Disease

13 = Growth Impairment

14 = Congenital Anomaly

15 = Learning/Cognition

16 = Multiple Body Systems

17 = Infectious Disorder

5. YOUR CHILD'S PRIMARY DIAGNOSIS ..

(please specify)

DPH use only

--	--	--	--	--	--

6. PLEASE DESCRIBE ANY OTHER HEALTH PROBLEMS

7. HOW DOES YOUR CHILD MOVE ABOUT MOST OF THE TIME IN THE PLACE WHERE YOU LIVE?

(please choose only one)

☐

01 = Child is carried

02 = Child crawls

03 = Uses manual wheelchair

04 = Uses power wheelchair

05 = Uses modified stroller

06 = Child uses bedcart

07 = Child is in bed

08 = Walks with a walker

09 = Walks with crutches

10 = Walks with a cane

11 = Walks with someone's help

12 = Walks without any help

13 = Other (please specify)

8. DO YOU OR SOMEONE ELSE NEED TO HELP YOUR CHILD MOVE AROUND WHERE YOU LIVE?

(such as to push a wheelchair)

☐

1 = Yes, all the time 2 = Yes, sometimes 3 = No

9. DOES YOUR CHILD USE ANY OF THE FOLLOWING MEDICAL DEVICES/EQUIPMENT NOW?

(check all that apply)

a ☐ Tracheostomy tube

b ☐ Oxygen

c ☐ Ventilator

d ☐ Suctioning equipment

e ☐ Central venous line

f ☐ Feeding tube

g ☐ Colostomy/ileostomy equipment

h ☐ Genito/urinary device

i ☐ Dialysis equipment

j ☐ Apnea monitor

k ☐ Other (please specify)

l ☐ If none, check here

10. DOES YOUR CHILD USE ANY OF THE FOLLOWING ADAPTIVE EQUIPMENT NOW?

(check all that apply)

a ☐ Hospital bed

b ☐ Hoyer or other lift

c ☐ Bathtub lift

d ☐ Bathtub seat

e ☐ Adapted potty

f ☐ Adapted chair

g ☐ Floorsitter

h ☐ Prone or supine stander

i ☐ Side lyer

j ☐ Therapy wedges, bolsters or balls

k ☐ Other (please specify)

l ☐ If none, check here

CHILDREN WITH SPECIAL HEALTH CARE NEEDS HOUSING ADAPTATIONS SURVEY
page 2 of 5
PLEASE PRINT. PLEASE ENTER NUMBERS IN UNSHADED BOXES ONLY.

ID NUMBER:

DPH use only

PART B: SERVICES FOR YOUR CHILD

This section asks about the services your child might receive where you live.

11. DO ANY HEALTH WORKERS, THERAPISTS, TEACHERS OR OTHERS NOW PROVIDE SERVICES FOR YOUR CHILD WHERE YOU LIVE? ☐

1 = Yes 2 = No, do not need them 3 = No, but need home services

11a. IF YES, ABOUT HOW MANY TOTAL HOURS A WEEK ARE THESE SERVICES PROVIDED WHERE YOU LIVE? ☐ ☐ ☐

12. HAVE HOME HEALTH CARE WORKERS OR ANYONE ELSE EVER BEEN UNABLE OR UNWILLING TO PROVIDE SERVICES FOR YOUR CHILD? ☐

1 = Yes 2 = No

12a. IF YES, PLEASE EXPLAIN (DPH use only) ☐

PART C: YOUR HOUSING SITUATION

13. WHAT IS YOUR CURRENT LIVING SITUATION? ... ☐

1 = Own house/condo 4 = Live in public housing
2 = Rent house/apartment 5 = Live in a friend's home
3 = Live in a relative's home 6 = Live in a shelter

7 = Other (please specify) _____

14. HOW LONG HAVE YOU LIVED THERE? ☐

1 = Less than a year 4 = 6 - 10 years
2 = 1 - 2 years 5 = More than 10 years
3 = 3 - 5 years

15. WHAT CITY/TOWN DO YOU LIVE IN? ☐ ☐ ☐

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(please specify) _____

16. DO YOU RECEIVE ANY FORM OF GOVERNMENT RENT SUBSIDY? ☐

(such as a Section 8 certificate, MRVP - old Section 707) ..

1 = Yes 2 = No 3 = Do not know

17. ARE YOU ON THE WAITING LIST FOR ANY TYPE OF HOUSING ASSISTANCE?

(please check all that apply)

a ☐ If no, check here

b ☐ Public Housing

c ☐ Section 8

d ☐ MRVP (old Section 707)

e ☐ Other _____

18. HOW MUCH DO YOU PAY FOR HOUSING EACH MONTH? ☐

(rent or mortgage and any condo fees)

1 = \$0 - \$100 4 = \$501 - \$700
2 = \$101 - \$300 5 = \$701 - \$900
3 = \$301 - \$500 6 = Over \$900

19. HAVE YOU EVER MOVED BECAUSE YOUR HOME OR NEIGHBORHOOD LOCATION COULD NOT MEET YOUR CHILD'S HEALTH CARE NEEDS?

(please check all that apply)

a ☐ If no, check here

b ☐ Landlord would not permit adaptations

c ☐ Home could not be adapted

d ☐ Too costly to adapt home

e ☐ Home too far from doctors/hospitals

f ☐ Neighborhood was unsafe

g ☐ Home care workers wouldn't provide services due to neighborhood safety issues

h ☐ Schools not adequate for child's special educational needs

i ☐ Home not located near public transportation

j ☐ Other (please specify) _____

(IF YOU ARE TEMPORARILY LIVING WITH RELATIVES/FRIENDS or IN A SHELTER, please SKIP to PART F: HOUSEHOLD INFORMATION and start with question 28)

PLEASE PRINT. PLEASE ENTER NUMBERS IN UNSHADED BOXES ONLY.

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PART D: YOUR HOME

20. HOW MANY BEDROOMS ARE IN YOUR HOME? ☐

1 = 1 Bedroom 3 = 3 Bedrooms 5 = 5 or more Bedrooms
2 = 2 Bedrooms 4 = 4 Bedrooms

21. WHERE DOES YOUR CHILD SLEEP MOST OF THE TIME? ☐

1 = Own bedroom 3 = Bedroom with adults
2 = Bedroom with other children 4 = Living room/family room

5 = Other (please specify) _____

22. HOW MANY OTHER PEOPLE SLEEP IN THE SAME ROOM WITH YOUR CHILD? ☐
(enter 0 if child has own bedroom)

PART E: HOME ADAPTATIONS

23. FOR EACH HOME ADAPTATION BELOW, PLEASE PUT IN THE BOX THE NUMBER YOU THINK IS BEST.
(please fill in ALL boxes)

1 = I/we need this
2 = I/we might need this
3 = I/we put this in
4 = This was already there
5 = I/we do not need this

General Access

A ramp to home/building ☐
A vertical platform lift to home/building ☐
A working elevator in home/building ☐
A stairlift/glide inside ☐
Wider doorways ☐
Threshold removal ☐

Electrical System

Rewiring to increase electrical power ☐
A backup electrical generator ☐
Additional electrical outlets ☐

Remodeling

Converting a 1st floor room into the child's bedroom ☐
Space for medical equipment ☐
Enlarging rooms for indoor wheelchair access ☐
Handrails in halls/stairways ☐
Kitchen adaptations ☐
Doorknob & faucet changes ☐

FOR EACH HOME ADAPTATION BELOW, PLEASE PUT IN THE BOX THE NUMBER YOU THINK IS BEST.

(please fill in ALL boxes)

1 = I/we need this
2 = I/we might need this
3 = I/we put this in
4 = This was already there
5 = I/we do not need this

Bathroom

Bathroom expansion ☐
Lift for bathtub ☐
Roll in shower ☐
Toilet adaptations ☐
Bathroom grab bars ☐
Sink adaptations ☐

Additional Adaptations

An intercom system ☐
Soundproofing ☐
Air circulation/ventilation ☐
Other (please specify) _____ ☐

(please remember to put a number in the box)

24. HAVE YOU HAD ANY OF THE FOLLOWING PROBLEMS MAKING ADAPTATIONS? (check all that apply)

- a ☐ If no adaptations, check here
- b ☐ Have not had any problems making adaptations
- c ☐ Difficulty finding money to make adaptations
- d ☐ Town ordinances/zoning restrictions limit adaptations
- e ☐ Trouble with design and/or finding materials
- f ☐ Trouble finding someone to help make adaptations
- g ☐ Other (please specify) _____

CHILDREN WITH SPECIAL HEALTH CARE NEEDS HOUSING ADAPTATIONS SURVEY
page 4 of 5
PLEASE PRINT. PLEASE ENTER NUMBERS IN UNSHADED BOXES ONLY.

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25. WHO PAID FOR THE ADAPTATIONS?

(check all that apply)

- a ☐ If no adaptations, check here
- b ☐ Self, with or without partner
- c ☐ Insurance Company
- d ☐ Extended family
- e ☐ Public Housing Authority
- f ☐ Landlord/Management Company
- g ☐ Community donations of time/materials
(please specify) _____
- h ☐ Reimbursement from State and Local
Government programs
(please specify) _____
- i ☐ Other (please specify) _____

26. TOTAL COST OF THE ADAPTATIONS?

(enter 0 for no adaptations)

- 1 = under \$250 5 = \$5,001 - \$10,000
2 = \$250 - \$1,000 6 = \$10,001 - \$20,000
3 = \$1,001 - \$2,500 7 = \$20,000 or more
4 = \$2,501 - \$5,000 8 = Do not know

27. IF YOU NEED TO MAKE ADAPTATIONS NOW BUT
HAVEN'T, WHAT HAS KEPT YOU FROM MAKING THEM?

(check all that apply)

- a ☐ If no adaptations are needed, check here
- b ☐ Adaptations are too costly
- c ☐ Rent and cannot make structural changes
- d ☐ Town ordinances/zoning restrictions limit adaptations
- e ☐ Do not know how to design and/or find materials
- f ☐ Do not know where to find someone to help us
- g ☐ Not sure of child's future needs
- h ☐ It is hard to make time to get the work done
- i ☐ Other (please specify) _____

PART F: HOUSEHOLD INFORMATION

28. WHAT IS YOUR RELATIONSHIP TO THE CHILD? ...

- 1 = Mother 6 = Other adult relative
2 = Father 7 = Other adult friend
3 = Adoptive/Step parent 8 = Professional caregiver
4 = Foster parent 9 = Other _____
5 = Grandparent

29. HOW WOULD YOU BEST DESCRIBE YOUR CHILD'S
RACE?

- 1 = White 5 = American Indian/Alaskan
2 = Black Native
3 = Hispanic 6 = Other _____
4 = Asian/Pacific Islander

30. HOW WOULD YOU BEST DESCRIBE YOUR
CHILD'S ANCESTRY?

- 01 = Puerto Rican 12 = Cambodian
02 = Dominican 13 = Vietnamese
03 = Central American 14 = Laotian
04 = Other Hispanic 15 = Other Asian
05 = Cape Verdean 16 = Pakistani/Asian Indian
06 = Brazilian 17 = European
07 = Portuguese 18 = African
08 = Haitian 19 = African-American
09 = Jamaican
10 = Other West Indian 20 = Other _____
11 = Chinese

31. WHAT LANGUAGE IS SPOKEN MOST OFTEN IN
YOUR HOUSEHOLD?

- 1 = English 5 = Haitian Creole
2 = Spanish 6 = Vietnamese
3 = Portuguese 7 = Laotian
4 = French 8 = Cambodian 9 = Other _____

32. WHAT IS THE TOTAL NUMBER OF PEOPLE LIVING
IN YOUR HOUSEHOLD, INCLUDING YOU?

33. WHAT TYPE OF INSURANCE DOES YOUR CHILD HAVE?
(check all that apply)

- a ☐ Private insurance (like Blue Cross or Harvard
Community Health Plan)
- b ☐ MassHealth (Medicaid)
- c ☐ CommonHealth
- d ☐ Medicare
- e ☐ CHAMPUS
- f ☐ Veterans Administration
- g ☐ No insurance
- h ☐ Do not know
- i ☐ Other (please specify) _____

34. WHICH CATEGORY BEST DESCRIBES THE TOTAL
HOUSEHOLD INCOME?

- 1 = \$0 - \$9,999 5 = \$40,000 - \$49,999
2 = \$10,000 - \$19,999 6 = \$50,000 - \$74,999
3 = \$20,000 - \$29,999 7 = over \$75,000
4 = \$30,000 - \$39,999

ID NUMBER:

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35. IF YOU COULD MAKE ONLY ONE ADAPTATION, WHAT WOULD IT BE? ☐

- 0 = Do not need any adaptations
- 1 = A ramp leading to the house
- 2 = Stairlift/elevator indoors
- 3 = Bathroom adaptations
- 4 = More space for family's privacy

- 5 = More space for child's privacy
- 6 = More space for medical equipment
- 7 = Other _____

36. ARE THERE ANY HOUSING RESOURCES YOU HAVE COME ACROSS THAT YOU WOULD LIKE TO SHARE WITH OTHER FAMILIES?

37. IS THERE ANYTHING ELSE YOU WOULD LIKE TO TELL US ABOUT YOUR HOUSING NEEDS?

THANK YOU FOR YOUR PARTICIPATION!

Please return your survey in the enclosed, stamped envelope to:
Lisa Sofis, MA Department of Public Health
Bureau of Family & Community Health, 150 Tremont Street, **7th Floor**, Boston, MA 02111

APPENDIX E
Case Management Eligibility Criteria
Massachusetts Department of Public Health

To be eligible for **Limited Service Coordination** or **Funded Support Services**:

- The child must be less than 18 years of age (up to 22 with the approval of Director of Family and Community Support) or an inactive or former client between 18-21 years old requiring transition to adult services.
- The child must have a chronic medical illness or physically disabling condition that has lasted or can be expected to last at least 12 months.
- The child or family has an identifiable need for services.
- Needed services cannot be secured through routine information and referral or technical assistance activities, but are likely to be obtained with the direct assistance of a case manager.

To be eligible for **Extended Service Coordination** the child must, in addition, meet at least two of the following criteria:

- Condition is life threatening
- Child is dependent on medical technology for normal functioning
- Family faces significant cultural, linguistic, or attitudinal barriers to service

Note: A detailed description of eligibility criteria for Case Management services is available from the Department of Public Health. The following is a summary statement of those criteria and should not be construed as the basis on which to judge potential eligibility of any particular child and family.

APPENDIX F

Family Survey Methodology Response Rates to Family Survey

SURVEY GROUP	NUMBER DISTRIBUTED	NUMBER RETURNED	RESPONSE RATE (%)
Case Management	528	421	80
Early Intervention	331	129	39
MA Hospital School	132	61	46
Franciscan Children's Hospital	22	13	59
Federation for Children	6	6	100
NE Medical Center	1	1	100

Survey Pre-test

Pre-testing of the survey was conducted with approximately 50 parents in six Early Intervention parent support groups.

Survey Distribution

Methods for particular parent groups were as follows:

Case Management client families received mailed surveys directly from project staff. The initial mailing yielded a response rate of about 60%. Two weeks later, a follow up postcard was mailed. One month later a call was made to each non-responding family, resulting in either mailing of a second form, or completion of the survey over the phone with families who expressed a willingness to participate.

Early Intervention Program client families received surveys from the directors of their EI programs. 47 out of 65 of the state's programs participated. Directors were asked to offer the survey to parents whom they felt might have a child with a disability that could require housing adaptations. To calculate a response rate for this group, EI directors reported the number of surveys they distributed.

Massachusetts Hospital School student families received surveys through the mail from school staff. Parents were sent a follow-up card one week later.

Franciscan Children's Hospital inpatient families received surveys from hospital staff either by mail or in person when they came to visit their children. In cases where language or literacy barriers existed, FCH staff assisted the families in filling it out.

Remaining survey responses came from *The Federation for Children with Special Needs* and *New England Medical Center*.

Techniques to increase the return rate for all groups within the overall sample included:

- inclusion of a self-addressed return envelope with the survey form
- provision of housing resource materials to families who returned the survey
- a raffle with donated prizes for those who returned the survey

APPENDIX G

Glossary of Equipment used by Children Dependent on Technology

1. **Apnea Monitor** -- a device which monitors breathing and sounds an alarm when respiration ceases or drops below a certain level.
2. **Feeding Tube** -- used to give feedings and medications when a person cannot take them by mouth. Specific types include:
 - Nasogastric tube** -- a tube that passes through the nostril, down the throat and esophagus, and into the stomach.
 - Gastrostomy tube** -- a tube inserted into a surgical opening through the surface of the abdomen and into the stomach.
 - Gastrostomy button** -- a "T" shaped plastic device held in place by a mushroom shaped dome in the surgical opening of the stomach.
 - Jejunal tube** -- a tube which delivers a feeding solution, medication or fluids to the small intestine, bypassing the stomach.
3. **Central Venous Line** -- an IV line that is surgically inserted into a deep, large vein in the neck or chest. It is used for long term delivery of intravenous fluids and/or medication.
4. **Colostomy/Ileostomy Pouch** -- a plastic pouch that covers a surgical opening in the large or small intestine and collects feces.
5. **Dialysis Equipment** -- removes the body's waste products in cases of impaired kidney function or absence of kidneys. Peritoneal dialysis introduces fluid into the peritoneal (abdominal and pelvic) cavity, then drains it by gravity. Hemodialysis circulates a patient's blood through semipermeable tubing in an artificial kidney.
6. **Genitourinary Devices** include:
 - Urostomy** -- an artificial site for urine to come out of the body. The opening for the urostomy is on the abdomen and is covered by a plastic pouch.
 - Urethral Catheterization** -- the removal of urine from the bladder by inserting a catheter into the urinary opening to the bladder.
7. **Oxygen Therapy** -- is administered through a nasal cannula, mask, mechanical ventilator or tracheostomy collar to facilitate respiration.
8. **Suctioning Equipment** -- removes secretions or mucus from the mouth, nose, throat, trachea or tracheostomy tube to ensure adequate air exchange.
9. **Tracheostomy Tube** -- a tube inserted into a surgical opening in the trachea (windpipe). This opening allows air to go in and out of the lungs.
10. **Ventilator** -- a mechanical device for artificial ventilation of the lungs when a person is unable to breathe sufficiently on his or her own.

